



Having your say?

The same as you?
National Implementation Group

Report of the Advocacy Sub Group



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SCOTTISH EXECUTIVE

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The Scottish Executive wishes to thank ENABLE, Equal Say and the Dunfermline Advocacy Project for providing the photographs in this report

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Introduction

The same as you? review of services for people with learning disabilities was published in 2000. It set out a 10-year programme of change that would support children and adults with learning disabilities and autism spectrum disorders (including Asperger's syndrome) to lead a full life, giving them choice about where they live and what they do. People with learning disabilities and family carers were involved at all stages of the review and their experience of life with learning disabilities shaped the vision for the future.

All of the recommendations are based on seven principles:

People with learning disabilities:

- should be valued
- are individual people
- should be asked about the services they need and involved in making choices about what they want
- should be helped and supported to do everything they are able to
- should be able to use the same local services as everyone else, wherever possible
- should benefit from specialist social, health and education services
- should have services which take account of their age, abilities and other needs.

The review was clear about the importance of advocacy in achieving these goals:

Better information, communication and advocacy are central to making any changes and putting the principles into practice. If we are to include people with learning disabilities and autism spectrum disorders fully in our communities, they need to have accurate information so they can make informed choices and decisions about their lives. People with learning disabilities need to be able to have their say. They need to be supported if necessary to make their point.

(The same as you? 2000 p. 42)

Some people with learning disabilities may also have an autism spectrum disorder or other disabilities and medical conditions. As a result, it is important that the full impact of these disabilities and medical conditions are taken account of when trying to meet their needs.

Who wrote this report?

A National Implementation Group was set up in 2001 to assist with the implementation of *The same as you?*. The Scottish Executive believed that the involvement of people with learning disabilities and family carers in implementing the findings of the review was just as important as it had been in carrying out the review. Members include 5 people with learning disabilities and 2 family carers. The group identified a number of priority areas that would be the main drivers for delivering the change programme. Advocacy was one of these.

When *The same as you?* was published it said not enough people were getting advocacy:

Many people with learning disabilities and autism spectrum disorders, their carers and professionals recognise that an independent person standing up for the person with a learning disability can help find the right solutions to very difficult problems. Although advocacy is now more widely available, our survey of users and carers found that it did not play a large part in people's lives. This suggests that there is a significant gap in the range of support available. Advocacy allows people to have a greater say in decisions which affect their lives. People with learning disabilities find it useful, and they enjoy the company and friendship that their advocates often offer. A user in our survey said: I just know her – she is my friend. I meet my friend, go out places...Ellen is there and Ellen helps me.

(The same as you? 2000 p. 47)

Recommendation 11 said: *'The Scottish Executive should continue to encourage the development of local independent advocacy services.'*

A short life working group was set up to look at progress with the development of advocacy for people with learning disabilities and autism spectrum disorders in Scotland. Membership included people with experience of using and supporting advocacy services. The list of members and the organisations they represented are in **Annex 6**.

What did the group do?

The group wanted to see how advocacy had progressed since 2000. There have been some developments in advocacy since *The same as you?* was published. These included the creation of the Advocacy Safeguards Agency (ASA) and the Scottish Independent Advocacy Alliance (SIAA). In late 2005 ASA was dissolved. More information about SIAA is in **Annex 3**.

Other national developments and policy guidance reflect the importance of independent advocacy in safeguarding the rights of individuals and in supporting individuals and groups to be involved in planning their care. These include, the work of the Scottish Commission for the Regulation of Care, the Adults with Incapacity (Scotland) Act 2000, Direct Payments, Fair for All, the NHS Patient Focus Public Involvement Framework, the Mental Health (Care and Treatment) (Scotland) Act 2003. We also looked at policies to encourage all people to be more involved in all aspects of public services, such as the National Standards for Community Engagement. **Annex 1** gives more detail on the legislative and policy background in which advocacy is developing.

The group set out to identify progress and good practice and to see what barriers could hinder progress with *The same as you?* They looked at information that was already available, such as the Advocacy Safeguards Agency's *Map of Independent Advocacy across Scotland*, information in the 2004-2007 Partnership in Practice Agreements, and the advocacy plans prepared by NHS Boards in 2004. Members gathered stories and case studies about people's experience of advocacy. They also issued questionnaires to people with learning disabilities, people with autism spectrum disorders, family carers and people in local agencies. This information has been used to get a better picture of when and how advocacy is being used, what it is achieving, how widely it is available and what needs to be done to make it more accessible and better understood. It is summarised in **Annex 5**.

What is this report about?

From the information the group gathered, it was clear that many people did not understand what advocacy is, nor the importance of independent services. There is also a need to understand the difference between consultation, involvement, and advocacy. The stories and case studies also showed how advocacy is not just about health and social care, but that sometimes when commissioning services there is a narrow focus on these issues. Advocacy affects and relates to the whole of life, whether that means accessing housing provision, participation in the local community services, or being safe in the community.

Individuals have a right to be heard and to be involved in all decisions that impact on their lives, regardless of a person's individual background. Independent advocacy is a crucial element of safeguarding and progressing civil and human rights, and of implementing the social justice agenda.

Research shows that people with complex needs are more at risk of a wide range of poor outcomes. These include:

- *Less choice about their lives*
- *Less involvement socially*
- *Fewer chances of employment*
- *Less active lifestyles*
- *Greater health needs*

And they are most likely to have difficulty expressing their needs and as a result need more help.

We need to build towards a position where everyone who has needs over and above their learning disability, for example, extra physical or mental health problems, or challenging behaviour, and everyone who is particularly vulnerable has ready access to an advocate.

(The same as you? 2000 p. 47)

Chapter 1 of this report describes how important advocacy is to people with learning disabilities and autism spectrum disorders, and how and when advocacy can make a difference to someone's life. **Chapter 2** explains what advocacy is and the different types of advocacy available. **Chapter 3** looks at the links between these different types of advocacy, and how they support person-centred services, help to avoid or resolve crisis situations and move people's lives forward. There are a number of issues that will impact on the future development of advocacy. These are also discussed in Chapter 3.

The report sets out some recommendations that aim to encourage people in every sector to take forward the provision of independent advocacy for people who need it. The aim of the report is to deliver better outcomes for people with learning disabilities and people with autism spectrum disorders.

Who should read this report?

This report emphasises the importance of advocacy in all aspects of life, and sets out some information about person-friendly services, policies and law, and useful resources. As well as people who work in health and social care, it is also relevant to people who work in a range of local authority services and associated agencies, including education, transport, lifelong learning, housing, and leisure and recreation.

Adults with learning disabilities and autism spectrum disorders, like any other adults, need learning opportunities throughout their lives. They want to learn skills for work, enjoy leisure activities, improve their skills (especially communication) develop self-confidence and self-advocacy, and learn to use facilities in their local communities.

(The same as you? 2000 p. 47)

This report will also be of interest to people with learning disabilities and their family members.

Acknowledgements

We would like to thank everyone who provided stories and case studies, and who completed our questionnaires. We have used this information in the report but have made it anonymous. It is used to illustrate individual experiences, and does not reflect an evaluation of the types of service referred to.



CHAPTER 1

Why having a voice matters

Introduction

Many people with learning disabilities and autism spectrum disorders find that some services do not treat them with respect, and do not listen to them. They are frequently not valued and not allowed to make the sort of choices that others take for granted. They end up being disadvantaged and discriminated against.

The reasons given during our consultation included:

- We often lack confidence to speak up and think we are not allowed to express an opinion
- We are not used to making choices
- Often we do not have the information to make choices
- We can easily be very intimidated in many of the situations where we would like to say what we want
- Some people do not give people with learning disabilities or autism spectrum disorders time to say what we want to
- People often have problems understanding us
- Some people with autism spectrum disorders have difficulties in communication, social interaction and understanding which makes it hard for us to say what we want

There are several things which can help people to have a voice.

- Other people need to listen and encourage someone to speak up for themselves. People need to have enough time to work out what they want to say and communicate in the way they find comfortable. They also need other people to treat what they say with respect. Sometimes training can help, but the people who contributed to this report were clear that people's attitudes and values are the starting points.
- Friends and family can stand with someone – encourage the person to speak up for themselves and offer moral and practical support if the person wants this. This is what many friends and relatives do for each other. We heard about many situations where someone's mum or friend had helped them speak up and get the opportunities or services they wanted.

- People need to have access to independent advocacy when they want to use this form of support. This might be because this person prefers not to involve a friend or relative, or because the person wants to keep this matter private, or because the matter is complicated and they want to have someone with particular experience standing beside them.
- Joining with other people who share your situation or experience can help. You can encourage and learn from each other. You can also join together to have a stronger collective voice.

All of these forms of support are important. In this report we are looking in detail at independent advocacy, including collective or group advocacy. This is because this support is particularly important for people who have the greatest difficulty speaking for themselves.

Advocacy is important for everyone. Another Sub Group has been looking at the needs of children who have learning disabilities or autism. Children and young people need to have access to advocacy that reflects their situation, and the suggestions we make in this report apply to them as much as to adults.

Sometimes family carers also need some help in having their say. This can be when they are trying to get the right services and opportunities for the person they care about. During the consultation for this report, carers told us about times when they were so upset or angry they found it difficult to explain what was needed. Carers also told us about how they sometimes needed help to get the support that they required for themselves. They said that what was needed was for other people to listen. They were also looking for advocacy for them as individuals, for the family as a whole, and for the person with the disability.

Why advocacy matters

In this chapter, the Vice Chairperson of People First Scotland describes why advocacy is important to people with learning disabilities.

Many people with learning disabilities experience times when they feel they are not being treated in the right way:

- People get bossed around
- They get told what to do
- They sometimes get abused

Things happen to them that they do not know about and would not agree to if they did know about them.

There are different kinds of advocacy which all try to make sure that people get treated right.

Who are People First?

People First is about self-advocacy. People First is run by its members and there are about 50 groups across Scotland. Most of them are based in local communities, some are in long-stay hospitals and a few are women-only groups.

The local members elect Directors to the Board of People First, which manages the organisation, staff and makes decisions about national policy.

People First has tried to get things changed in different ways, recognising always that real change needs to happen inside people themselves, as well as in the way that people are seen and treated by others. All of this means that sometimes policies and services need to change.

It has been our experience at People First that all of our members can grow and develop into different people.

- People who can do things.
- People who have rights.
- People who are worth spending time with and being loved.

We use the staff and volunteer advisers to support people in speaking up for themselves and for other people.

This has, over the years, led us to try to promote the voice of people with learning disabilities.

We campaign on things like hate crime and hospitals closing. All of which is achieved by meeting with Ministers in the Parliament; writing letters; producing petitions and speaking at meetings, universities and colleges; playing a part in health, social work and care inspections. Our work extends across Scotland but also on a European and world stage.

We would not want to say that People First is better than other kinds of advocacy. We also work with independent advocacy organisations who advocate for individuals.

Most of the time when one of our members has a big problem, we look for another advocacy organisation to work with them. Unfortunately all too often we are told that due to resources there is not one available in the area or, if there is, there is a long waiting list.

We would want to say that People First is important. It makes a big difference in the lives of our members. We think it helps people believe in themselves more. We think it helps other people look in a different way at people with learning disabilities.

One of the best things about People First is that it helps our members feel strong enough to speak about their life for the first time. It sometimes takes a long time before people understand that what's happening in their lives is not right. A lot of the time, that means the person could use an advocate to help them change things or stop some abuse happening. That makes advocacy, whether undertaken by us or by others, all the more important.

Why having a voice is important for people with autism spectrum disorders

People with autism spectrum disorders have impairments in social interaction, communication and imagination. As a communication disorder, some people will need help to express what they want whether it be what they want for dinner to accessing appropriate services.

Asperger's syndrome is part of the autism spectrum, but people with Asperger's syndrome tend to have average or above IQ levels and appear to have good language skills which can mask their difficulties they may have in understanding a situation and communicating what they really want.

As a result, some advocacy services may feel they don't need support in expressing themselves because they appear too able and articulate.

Independent advocacy organisations need to be aware of the various aspects of autism spectrum disorders in order to help all those on the spectrum who require support.

As part of implementing the Public Health Institute for Scotland needs assessment report for autism spectrum disorders, local agencies are being asked to ensure frontline staff have training in working with people with autism spectrum disorders.

A report found that those that accessed independent advocacy services had positive experiences e.g. *'Yes I'm very happy with my advocate, I only wish I knew her all those years ago.'*¹

However, there were others in the report who found it difficult accessing an independent advocate. Only 11% of carers said that the adult they cared for had ever used an independent advocate with 54% saying they were not aware of an independent advocacy organisation in their area that the person they care for could use.²

1 Broach. S, et al (2003) *Autism: rights in reality*. London: NAS

2 *ibid*



CHAPTER 2

What is independent advocacy?

Advocacy:

- IS about standing alongside people who are in danger of being pushed to the margins of society
- IS about standing up for and sticking with a person/group and taking their side
- IS a process of working towards natural justice
- Is NOT counselling
- Is NOT befriending
- Is NOT care and support work
- Is NOT consultation
- Is NOT telling or advising someone what to do
- Is NOT speaking for people when they are able to express a view
- Is NOT mediation

Why there is a need for independent advocacy

Some people in society are treated differently from others for many reasons including their disability, gender, age, ethnicity or religion. Many people with learning disabilities often have little control over their own lives. This can mean that they are unlikely to be able to fulfil or demand their basic human rights.

Independent advocacy aims to support people to become active and valued members of society. Independent advocates are in a good position to do this because they do not have any conflicts of interest or their own agenda.

Independent advocacy is about:

- helping people to have their say and to be heard
- safeguarding people who are vulnerable and discriminated against or whom services find difficult to support
- empowering people who need a stronger voice by enabling them to express their own needs and make their own decisions
- enabling people to gain access to information, explore and understand their options, and to make their views and wishes known
- speaking on behalf of people who are unable to do so for themselves
- being independent – separate from service providers and funders

This means that the advocate or advocacy organisation:

- is not connected with carers or services that have a strong influence on the life of the person being supported
- does not focus on their own personal interests
- can concentrate solely on supporting his/her partner or needs of the group in the case of group or collective advocacy

The aim of independent advocacy is to:

- help people have their say
- add weight to a person's ideas, wishes and opinions
- challenge attitudes and perceptions
- socially include people
- protect people's rights

Independent advocacy is important because:

Individuals may experience

- social isolation and exclusion/prejudice
- not being listened to by services
- a lack of independent support
- a lack of skills, confidence and experience
- a lack of community contact with services

Independent advocacy works by:

- supporting people to represent themselves
- being loyal
- being focused on what needs to be done
- following the person's agenda
- being involved and being prepared to act
- working with those most at risk
- acting outside of the service system

How independent advocacy organisations are structured

Board of Directors/Management Committee

Independent advocacy organisations are usually governed by either a Board of Directors or a Management Committee, whose sole responsibility is the management of that advocacy organisation. Board/Committee members should be independent of service providers and/or funders in order to ensure that the organisation is structurally independent of those bodies.

Staffing structure

Staff in an independent advocacy organisation, whether paid or volunteer, in as much as possible should not be employed in other organisations that provide services or funding to that advocacy organisation. This is to ensure that the advocacy organisation and those who work as advocates are independent, and to prevent the potential for conflict of interest.

Managing the potential for conflict of interest

It is recognised that in certain areas of Scotland, the main employers are the NHS and the local authority. Independent advocacy organisations in these areas, staff (paid and unpaid)/citizen advocates/management committee members may be employed by one or other of these organisations. It is important that there is a policy in place to manage the potential for conflict of interest.

General funding

Independent advocacy organisations receive their core funding from the local authorities and NHS Boards. Organisations access other funding from a variety of charitable and grant-making trusts and agencies. From October 2005 with the introduction of the Mental Health (Care and Treatment) (Scotland) Act 2003, there will be responsibility placed on all NHS Boards to ensure all individuals – children, older people and other adults – with mental illness, learning disabilities, dementia or personality disorders have access to independent advocacy.

Types of independent advocacy

Citizen advocacy

- encourages ordinary citizens to become more involved with people in their communities who might need support
- is based on trust between the person being supported (advocacy partner) and the advocate
- means the advocate's loyalty is to the person being supported not to the advocacy project
- means the advocate is not paid
- means the advocate will build a personal relationship with their advocacy partner
- means the advocate will support their advocacy partner using their natural skills and talents rather than being trained for the role.
- means the advocacy relationship will be on a 1 to 1 basis and long-term.

A citizen advocate is 'A valued citizen, who is unpaid and independent of human services, creates a relationship with a person who is at risk of social exclusion and chooses one or several of many ways to understand, respond to, and represent that person's interests as if they were the advocate's own, thus bringing his/her partner's gifts and concerns into the circles of ordinary community life.' (John O'Brien, Georgia Advocacy Office 1987)

An example of a situation in which citizen advocacy could work to help an individual lead a valued and fuller life would be:

Matthew has an autism spectrum disorder. He has been living independently for the last 10 years. His family had great difficulty in understanding his condition and they no longer get on.

Matthew was involved in a local community project aimed at improving the relationship between different minority ethnic groups in the area. Some local residents would shout abuse at Matthew and graffiti was daubed on his house. The police were called but no further action was taken. Since this incident the abuse has continued. More recently, Matthew has been physically attacked within his own home and hospitalised.

Matthew finds it difficult to co-ordinate information from different people, therefore it is difficult for him to pursue complaints with the police and the local authority. He has no-one to support him in pursuing complaints or find information that might help him. Matthew is becoming increasingly frustrated by his situation and still feels at risk of verbal and physical attacks.

Advocacy can widen and deepen someone's access to other non-health and social care services within the community, as shown by Jenny's story:

Jenny has been living on her own for four years after a considerable length of time within a hospital environment. She continually attempted to access the local leisure centre but every time she went she was told by reception staff that she could not use the equipment or facilities without a support worker present to 'supervise' her.

Jenny was getting increasingly upset and alarmed about this situation and mentioned it to her advocate. Together they decided how they were going to tackle the situation, and together they went and spoke to the manager of the leisure centre. As a result the staff of the centre underwent awareness training, and Jenny, along with her friends, can independently and without obstruction use the leisure facilities. She has said that without her advocate's help she might still be being turned away.

Individual professional advocacy

This can be provided by people who are paid or working on a volunteer basis. It:

- aims to support people to represent their own interests.
- aims to represent the views of individuals if the person is unable to do this themselves.
- provides support on specific issues.
- provides information not advice.
- provides short or long term support.
- an advocate may support several people at any time.

Freda

Freda is a 35-year-old woman with a learning disability who was diagnosed with dementia 12 months ago. Due to family circumstances a decision was made that Freda should move to a nursing home. Eventually Freda was moved into a unit that specialised in dementia. The other residents in the unit were all in their eighties and were in the later stages of dementia.

Freda's social worker referred her to the independent advocacy organisation, and Susan the advocate began working with Freda. At first this was difficult because Freda's verbal communication was very limited but as Susan got to know Freda she found out that Freda was very unhappy about living in the unit and wanted to live on her own in her home town, not far away.

Susan spoke to Freda's care team about the unit being inappropriate for Freda's needs. Eventually Freda's care team agreed that the unit was inappropriate for Freda and began the process of arranging more appropriate accommodation. Following several review meetings Freda told the care team, through Susan that the sheltered house that she had been offered was where she wanted to stay. As this is in the neighbouring local authority area Susan worked with Freda to find another advocate to support her for the first three months after the move.

Freda's life has changed a lot, she is glad that she met Susan because without her advocate Freda thinks she would still be at the dementia unit. Freda misses Susan but she has a new advocate who is just as good.

Group advocacy

- is a group of people who are all facing a common issue who get together to support each other.
- the group may take the form of a patients' council in a hospital, a residents' forum in a care home or a group in the community.
- individual members of the group may support each other over specific issues
- the group as a whole may campaign on an issue that affects them all

Some of the benefits of group or collective advocacy are:

- An issue may arise that is to do with the planning of services and their impact on a group of people. Therefore the collective voice can be stronger than that of the individual. Groups are difficult to ignore.
- Raising a difficult issue can be an isolating experience for one person. The group experience can reduce isolation and provide support.

The Patients' Council

The Patients' Council was set up a few years ago by a group of people at a learning disabilities hospital that was facing closure. At first the group faced lots of problems because not all the staff in the hospital understood why they were formed or what they did. The Patients' Council has a support worker who organises meetings, papers and anything else the Council is working on.

The first group of people who were moved out of the hospital into the community were not really consulted about where they were going to live or who with. The Patients' Council has made sure that when a persons move from the hospital into the community is being planned that they are involved from the beginning. The person is consulted about everything and has choices about their future.

The Patients' Council quickly began working to improve the lives of the people in the hospital. For many years they had wanted access to drinking water on the wards, the hospital management had said that the hospital could not afford water coolers on every ward and that people could get water from the patient toilets at any time. Eventually the hospital management agreed that getting water from the water coolers was more dignified and respectful and now all the wards have water coolers.

The Patients' Council has changed the lives of the hospital residents in other ways too, its given people a lot more confidence to speak up and challenge the things they would not normally challenge. Some people on a ward were unhappy about the way that staff spoke to them, they were not comfortable about challenging these staff or formally complaining about them. Therefore the Patients' Council raised the issue with hospital management, after the complaint was dealt with all staff were given training on attitudes and anti discriminatory practice. The Patients' Council was involved in the delivery of this training.

Self-advocacy

- is a group of people who are using or have used care and support services in the community, which are provided and/or funded by the local authority or NHS board.
- the group identifies relevant issues and it's the group's point of view that is put forward.
- the group may not have a formal structure and name, and may be self-governing.

Self-advocacy organisations often require substantial resources because many people only become self-advocates after much support to develop their skills and confidence.

Anita

Anita is a 36-year-old woman with a learning disability. Anita didn't have many friends and didn't see her family much. Anita regularly attends a day centre for adults with a learning disability. At the day centre she found out about a self advocacy group. Anita was unsure about going to this group because she didn't know what self-advocacy was or what would happen in the group.

The self-advocacy support worker, Moira talked to Anita about the group and explained what the group does. Moira said that the group helped to make changes for people with a learning disability by talking to local social work managers. Moira explained that the group decide what they want to talk about and what they should do about things that effect people with a learning disability. She also explained that the group decides who can be a member and come to their meetings. Moira said that she worked for the group to help organise meetings, etc.

Moira invited Anita to meet some of the members of the self-advocacy group to find out more. Anita felt comfortable with Moira and decided that she would like to find out more. Anita joined the self-advocacy group, at first she found it difficult because everything was new to her but the other members of the group and Moira gave her lots of support and encouragement and were happy to explain things to her.

The self-advocacy group has helped change the way that social workers in the area work with people with a learning disability. Social workers now consult people properly before any changes are made in the way they are supported. Two years later, Anita is still a member of the self advocacy group, she feels ok about speaking at meetings, she has a lot more confidence and lots of friends.

Action Points

- The Scottish Independent Advocacy Alliance (SIAA) should make information widely available, that explains what independent advocacy is and what the different types of advocacy are and can do. The Executive, NHS Boards and local authorities should also make sure that this happens, under the Mental Health Act statutory agencies now have a duty to ensure that this happens.
- The Scottish Executive should ask local advocacy plans to show how people with learning disabilities and people with autism spectrum disorders will be able to have a choice of advocacy projects and a choice of advocates. Commissioners should ensure that there is choice in the advocacy available. The needs of people with a learning disability and people with autism spectrum disorder should be taken into consideration when commissioning services and people should be involved in the advocacy planning process.
- As part of the Joint Inspections of learning disability services, the Social Work Services Inspectorate (SWIA), the Care Commission, NHS Quality Improvement Scotland (QIS) and others should ensure organisations which provide services have systems in place to make sure that staff know what their roles are. People who work in services should know how they can work with independent advocacy projects and with other people who care about the people who use their services. The Care Commission and NHS QIS should consider what information the organisations give out to the people they support, families, advocacy projects and other organisations to help avoid people getting confused about roles.



CHAPTER 3

What needs to happen

Dilemmas of effective advocacy

This section is based on what we have heard from people with learning disabilities, families, advocacy projects and people who commission and work in direct care services. We want to learn from the good experiences around advocacy that people have had, so these happen for everyone. We also want to learn from what has not worked so these things do not happen again.

Being clear about people's roles

Sometimes a person will want to have an advocate because they want everyone's roles to be clear.

We recognise that it is within the role of many professionals – such as social workers, nurses and support workers – to advocate for people who use their services, as part of their job. However, it must be recognised that paid workers have divided loyalties – to their client and to their employers. There is always the possibility that these two loyalties will clash. That is one reason why independent advocacy is necessary, so that someone can have an advocate who is not limited in his/her power to act by any conflict of interest.

Independent advocates are still resisted in some cases where a worker feels that he/she is the person's advocate. Some professionals feel that the advocate is implying they can not do their job properly, just by being there!

The role of the advocate needs to be well understood. At the same time, people who work in services need to be clear about, and confident in, their own role.

It can also be hard for families and friends, who want the best for someone, to know when they should stand back and let the person with learning disabilities make their own choices and say what they want. Sometimes the individual and the family members want different things.

Action Points

- SIAA and advocacy projects should continue to explain what independent advocacy is and what the roles of advocates and projects are.
- SIAA should work with People First, carers' organisations, and other networks of people who have learning disabilities and autism spectrum disorders, to develop accessible information for families. It should help families know what they can do to help people have their own say, how to raise their ideas and concerns with services, and how to work with independent advocacy projects.

Challenging the status quo

The reason we need advocacy is to help people who have very little power to have the same power as everyone else.

Advocates still regularly tell stories of being undermined by staff who do not want to lose their power over the person they are supporting. Most people with learning disabilities still feel relatively powerless compared to their support workers and other professionals in their lives. Advocates align themselves with their advocacy partners, and therefore are also quite vulnerable.

It is easy for staff who work in services – especially when the person with learning disabilities lives in hospital or in a residential setting – to make things difficult for advocates by, for example, not inviting the advocate to meetings, not passing on information, arranging doctor's appointments at a time the advocate is due to visit, or by not letting the person meet with their advocate in private.

It is also possible to make things easy for the person with learning disabilities by making practical arrangements that do include the person's independent advocate. Similarly, if this is what the person wants, the arrangements can make it easy for a friend or relative to be there.

It may well be that these incidents where advocates are excluded are occurring less as advocacy becomes more accepted, but we have heard it is still quite common practice.

Action Points

- SIAA should work with advocacy projects and organisations that provide services to develop training for advocates that addresses the issues around power and helps advocates handle these situations effectively.
- All residential settings must have places where people can meet their advocate in privacy and comfort.

Risk averse society

Advocates have at least two responsibilities: first, to pursue the wishes of their advocacy partner; secondly, to keep them safe from harm, especially serious harm such as abuse. For much of the time, these responsibilities coincide. But there will be situations which raise dilemmas.

The first dilemma around risk is for an advocate: if my role is to pursue my partner's wishes, and my other role is to protect my partner from harm, what do I do when my partner wants to take a course of action that may lead him into harm?

A second dilemma is for service agencies that commission or provide services to people with learning disabilities. In a way it is the same dilemma. On the one hand, *The same as you?* has encouraged the view that people with learning disabilities should have as much say as possible over their own lives, and many services agencies try to put that principle into their services. On the other hand, there is some pressure on these agencies to act in a risk averse way. This is a key theme in the 21st Century Social Work Review. Therefore, the dilemma is: What do we do when someone with learning disabilities says they intend to take a course of action that may be risky? And what do we do when an advocate states this on the person's behalf?

This is a huge dilemma for an agency or person that feels they would be severely criticised if someone whom they support ends up harmed. It is a huge dilemma for a social work department that has a statutory responsibility to protect someone who is deemed to be vulnerable. It is all too easy to err on the side of caution, and automatically try to prevent someone from taking the risky course of action in the first place.

Many people with learning disabilities and many advocacy projects have told us that this is a fairly common scenario. Advocates have been asked to support someone to be allowed to act in a way that might be described by someone else as risky, but which the person thinks is a normal part of having a good life like everyone else. These situations include:

- getting involved in a relationship
- moving away from the family home
- staying out late
- getting drunk
- smoking
- having a child

People have also told us how they had worked out ways to reduce the risk of anything going wrong – often through talking over their plans with people they trusted, and sometimes including an advocate. But an assessment was made by someone who didn't have all the details and had not asked them about their plans.

Many people with learning disabilities report having plenty of people trying to keep them safe, but not too many supporting them to take risks. Therefore, what they usually want advocates to do is support them to take the risk. This is something some people with learning disabilities told us they feel extremely strongly about.

When advocates are asked to represent someone's wishes to do something risky, it can help everybody. Responsible advocates will not only represent someone's wishes, they will also try to make sure that that person is fully informed about the possible consequences, and is making an informed decision. This can help reassure everyone – relatives, professionals and people in the wider community – in that person's life, who may be worried that they will be blamed for any harmful outcome.

There needs to be an ongoing debate between the need to protect and reduce risks for those who are most vulnerable and the rights of individuals to lead free, full and fulfilled lives. People with learning disabilities have told us that they want to be part of that debate. They want other people to hear their experience and suggestions on what can help people understand and manage risks.

Action Points

- As part of developing policy and legislation relating to the protection of those who are seen as vulnerable, the Scottish Executive should consider the need for advice to the NHS, local authorities and care providers on how people with learning disabilities and their advocates should be part of assessing risk for each person and agreeing on how to reduce risks for that individual.
- The Scottish Executive should ask each local authority and NHS board to work with people with learning disabilities, families, collective/group advocacy organisations and self advocacy groups in their area to develop policies for people assessing and minimising risks for themselves.
- The Scottish Consortium for Learning Disability should identify and share good practice in risk management.

Consent

During the consultation on this report it was put to us that advocates should only be able to act as advocates for people who have the capacity to consent. Another way of saying this is that people who do not have the capacity to consent are not able to have an advocate.

People with disabilities and families told us how important it was that a potentially vulnerable group of people are not made more vulnerable by being denied this right to independent advocacy.

We agree with the view that capacity to consent should not be an issue in whether someone has access to independent advocacy.

It is stated in the Mental Health (Care and Treatment) Act that anyone with a mental disorder has the right to access advocacy services. The definition of 'mental disorder' in the Act includes people – children and adults – with a learning disability.

The Adults with Incapacity Act makes it clear that people are not simply 'capable' or 'incapable'. There are degrees of capacity, and there are some situations where someone can give consent and others where the same person cannot give consent.

It is useful to remember that advocacy projects have developed good practice for situations like this:

- Wherever possible, advocates find out what it is that their partners' wishes are.
- This can take a long time – it should be borne in mind that long-term advocacy is a preferable model in these situations.
- There are situations when the advocate may acknowledge that she does not know what her partner wants, yet her presence may be useful. In a situation where decisions are being made by service professionals about her partner, she may be the only person around the table who doesn't have a conflict of interest. In situations like this, the advocate's view is no more than her view, but it should still have some weight.
- There are other situations where consent seems unnecessary, for example when someone is being abused or neglected, or having their human rights denied. In these situations it seems appropriate that an advocate should speak up on behalf of her partner.

What advocacy projects cover

The people across Scotland who told us their experiences were clear that advocacy should help them get good support and achieve their rights in all aspects of their lives.

Issues where people with learning disabilities and families said they wanted some extra help to say what they wanted included:

- employment
- housing
- transport
- education
- moving from school and children's services to adult life and services
- health services
- social work services
- assistance with social integration and using ordinary community services
- access to services to support people with learning disabilities in their role as parents
- financial services
- police and community safety services

But many advocacy projects concentrate on health and social care issues. They receive all or most of their funding from social work or health budgets. Sometimes the funders have said they expect the project to do work that relates to people's use of particular services, and sometimes it is implied. Other projects have told us that they have more flexibility and can address whatever people with learning disabilities want to raise.

There are implications for advocacy projects being treated by commissioners in the same way as most other services for matters like geographical boundaries, age of the people they support etc. Freda's story shows how inflexible approaches around the geographical scope of an advocacy project can disrupt advocacy support at a time when it is needed and disrupt relationships based on trust. The outcome described here may have been the best outcome in that situation, but it raises wider issues.

Action Points

- Local advocacy plans for each area should state how people can get advocacy support on issues such as housing, transport and the other issues that people in that area say are important.
- Advocacy organisations need to be more proactive in seeking wider funding sources to enable them to provide advocacy to a wider range of people, and should not be solely reliant on one source of funding.
- The Scottish Executive should give advice to funders that their policies and practices should expect and enable the projects to focus on the needs of the individual. For example, funders should get advocacy projects to build in some flexibility for situations when someone who is already in touch with an advocacy project moves to another area.
- SIAA should work with advocacy projects to develop advice on ways to build in flexibility so advocacy projects can continue to meet the choices of the people they support.
- SIAA alongside other appropriate individuals and organisations, should develop national protocols for advocates working with people who do not have capacity.

- Staff in local authorities and NHS Boards and other people who are implementing the National Standards on Community Engagement should look at how people with learning disabilities and autism spectrum disorders are included as part of community engagement on all issues. As part of this, they should consider how independent advocacy projects can contribute to enabling people to have their voices heard.

Training

Throughout our discussions the issue of training came to the fore time and time again. There is still considerable uncertainty about what advocacy is and what the role of an advocate should be. The importance of developing and equipping staff with a general understanding and improving the skill base of existing advocates is self evident. We recognise that training needs to take place at various levels and at different times.

- Training for staff and professionals who work in the health and social care sector is of primary importance and those with professional responsibility should consider including awareness raising on advocacy as a matter of priority, not least given the centrality of advocacy in the Mental Health (Care and Treatment) Act.
- Training for staff who work in other sectors, such as, housing, criminal justice, and the police would also be beneficial. Increasingly advocates would find their services being properly used outside the narrow social care and health spheres.
- Training and the need to develop a national and coherent approach to learning and mutual development again raises the importance of resources. Commissioners should consider it a priority that advocacy projects are properly funded to ensure that ongoing training and staff development is factored in to agreements. Commissioners should also look at how their organisations can include advocacy projects in training that they are providing or funding.
- Any training offered should include the individuals who use advocacy at its heart. There is already good practice in training programmes offered by SIAA and others.

- There are also a whole set of issues around training in relation to communication, not least with regard to autism and Asperger's syndrome. **Annex 7** highlights a helpful guide to some of the issues raised.
- Commissioners should monitor the degree to which projects are keeping abreast of communication developments and issues both in training and practice.

Action Point

- SIAA and organisations with responsibility for training should ensure training for staff who provide services identifies the importance of independent advocacy and explains their role in working with advocates.

Diversity

People with learning disabilities told us how service providers often do not understand that people who have learning disabilities are as diverse a group as any other group of people in Scotland. They include people from minority ethnic communities, people whose first language is not English, people who are gay, lesbian, bisexual and transgender, and people who have a range of disabilities and health problems. They have also told us that often when they look to advocacy projects to help them get support which reflects each person's own circumstances, the advocacy project isn't very good at responding to diversity. Sometimes, this is because of the way the projects are funded – for example, all people who have a learning disability have to go to the project for their area, rather than choose an advocacy project in another area that suits them. Sometimes, it is because the staff or volunteers haven't had much training around diversity.

If there is more flexibility and choice for people with learning disabilities in where they get advocacy support, this would solve some of these problems.

Other actions that would help are advocacy projects doing more to respond to diversity in every aspect of their work.

Action Point

- Statutory organisations that fund advocacy projects should make sure projects are able to reflect the diversity of the people who want advocacy support. Advocacy projects should have premises that are easily accessible, comfortable and welcoming. There should be partnerships between advocacy projects supporting people who have learning disabilities and projects led by people who share other circumstances. People should be able to have a choice in which advocacy projects they use and in their advocate.

Children, young people and older people

In many parts of the country there are no advocacy projects for people aged under 18 who have learning disabilities. The new Mental Health Act and the Additional Support for Learning Act both say that children should have access to advocacy. Getting advocacy for problems around education is important, but this is not the only issue which people told us matters to children and young people.

Another issue which was raised is the type of advocacy available for children and young people. We heard of some projects where citizen advocates who are also younger have been recruited, but this is still unusual.

There are similar problems for people who have learning disabilities when they get over the age of 60 (or 65 in some areas). We heard how people can fall between the advocacy projects that there are for people with learning disabilities and the projects for older people.

Action Points

- Local advocacy plans should specify how children and young people, and older people who have learning disabilities and autism spectrum disorder will get access to advocacy on the points that are important to them, and in a form they find useful.
- Monitoring of local plans should measure the level of service against standards that address the needs of people with learning disabilities and autism spectrum disorders of all ages.

Funding for advocacy projects

People with learning disabilities and families told us how they were worried that funding for existing advocacy projects would be reduced or cut, and how there didn't seem to be enough funding for more projects in places where there was little advocacy support available. A particular concern is around advocacy projects which were set up when a hospital was closing, and where the funders seem to assume that the job of the project is over once the hospital has closed. People who were denied the chance to gain the confidence and skills to explain what they want during the years they spent in hospital may want to continue to make other changes in their lives.

Advocacy projects also told us how they felt there was a lot of uncertainty about their position from year to year, and how this could make it difficult to maintain staffing and volunteering levels.

We looked at levels of funding for advocacy in each local area, and at the types of projects that are funded, especially by local authorities and the NHS. A summary can be found in **Annex 4**.

The sources of funding, as well as levels of funding, can cause problems. As we have already noted, in some places the funders expect that if the funding is from health and social work budgets, the advocacy projects should concentrate on that. In other places, the view seems to be that whatever budget is used, what matters is supporting people with learning disabilities to have a good life.

Action Points

- Advocacy services need to be flexible to address the different levels of need people have throughout their lives. This will include periods of transition, for example where people are moving into the community as hospitals close, or where children move between special and mainstream or school and college education.
- Advocacy supports individuals to be included in society and is not just for health and social services. Consideration should therefore be given to the contribution of wider health and local authority departments to funding advocacy services, in order to deliver a whole range of services properly and effectively. Advocacy will also be helpful in achieving full public involvement, moving forward many initiatives such as Modernising Government and creating inclusive communities.

- Statutory commissioners of services and advocacy organisations need to develop clearer systems for recording who is using advocacy.
- The SIAA should develop national guidance for monitoring advocacy, to ensure that there is a consistent approach across Scotland.

Accountability for advocacy

We heard from people with learning disabilities and families about good experiences when the advocacy project was accountable to them and they felt they were in control. We also heard from people whose experience was that the advocate seemed more concerned with what other organisations or their funders would think – where they would go so far but then stop, for fear of rocking the boat.

We heard from advocacy projects about situations where they were expected not to challenge too much, and from staff in services and funders who thought that advocacy projects should work to promote the local policies.

We also heard of situations where the advocacy projects and the people who funded advocacy had discussed how the project could be as independent as possible and be accountable to the advocacy partners first and to other people after that.

We heard from advocacy projects which felt they had to pay too much attention to counting how many people used the project and activity levels, and were never asked about the outcomes for people who came to them looking for help in making their lives better. We also heard about some projects which did not seem to respect that they were receiving public money, or who were not giving a good quality of advocacy support.

The working group feel strongly that the accountability of an advocacy project is to people with learning disabilities and the other people whom advocacy projects support. In the first instance, this is to the advocacy partner. But it is also to all the other people with learning disabilities who want to have good quality advocacy.

We think that there needs to be more discussion over the next few years about what we mean by good quality advocacy, and how advocacy projects are accountable to people with learning disabilities. The starting point should be the same as the starting point for advocacy – the people who have limited power setting the agenda and having more choice and more power.

Action Points

- The Scottish Executive should continue to make clear to commissioners that whilst they obviously have a duty to make sure their funds are being used properly, they must allow projects to be appropriately independent and must not try to unduly influence the delivery of advocacy.
- The SIAA should work with people with learning disabilities and families, advocacy projects and funders, to find ways to describe what advocacy projects do which highlight their benefit for a person with learning disabilities. SIAA should spread the experience of projects and funders that are good at assessing and describing what advocacy projects do.
- The advice from SIAA and the Scottish Executive should establish that advocates are able to challenge services, the commissioners and their own advocacy project if this is in the interests of the advocacy partner.

Conclusion

This report sets out a number of action points for improving the quality and accessibility of advocacy to people of all ages, with learning disabilities and with autism spectrum disorders in Scotland. The following annexes describe person-centred services, set out good practice, and provide information to help individuals, families and people who provide a range of services as they work to contribute to inclusive, supportive communities.

The action points throughout the report are set out here so people can see where the next steps lie. However, these action points need to be seen as part of a much wider agenda where most people in society have some contribution to make to understanding and responding to the needs of people with learning disabilities and autism spectrum disorders, and achieving the goals set out in *The same as you?*.

Action Points

1. The Scottish Independent Advocacy Alliance (SIAA) should make information widely available, that explains what independent advocacy is and what the different types of advocacy are and can do. The Executive, NHS Boards and local authorities should also make sure that this happens, under the Mental Health Act statutory agencies now have a duty to ensure that this happens.
2. The Scottish Executive should ask local advocacy plans to show how people with learning difficulties and people with autism spectrum disorders will be able to have a choice of advocacy projects and a choice of advocates. Commissioners should ensure that there is choice in the advocacy available. The needs of people with a learning disability and people with autism spectrum disorder should be taken into consideration when commissioning services and people should be involved in the advocacy planning process.
3. As part of the Joint Inspections of learning disability services, the Social Work Services Inspectorate (SWIA), the Care Commission, NHS Quality Improvement Scotland (QIS) and others should ensure organisations which provide services have systems in place to make sure that staff know what their roles are. People who work in services should know how they can work with independent advocacy projects and with other people who care about the people who use their services. The Care Commission and NHS QIS should consider what information the organisations give out to the people they support, families, advocacy projects and other organisations to help avoid people getting confused about roles.
4. SIAA and advocacy projects should continue to explain what independent advocacy is and what the roles of advocates and projects are.
5. SIAA should work with People First, carers' organisations, and other networks of people who have learning disabilities and autism spectrum disorders, to develop accessible information for families. It should help families know what they can do to help people have their own say, how to raise their ideas and concerns with services, and how to work with independent advocacy projects.

6. SIAA should work with advocacy projects and organisations that provide services to develop training for advocates that addresses the issues around power and helps advocates handle these situations effectively.
7. All residential settings must have places where people can meet their advocate in privacy and comfort.
8. As part of developing policy and legislation relating to the protection of those who are seen as vulnerable, the Scottish Executive should consider the need for advice to the NHS, local authorities and care providers on how people with learning disabilities and their advocates should be part of assessing risk for each person and agreeing on how to reduce risks for that individual.
9. The Scottish Executive should ask each local authority and NHS board to work with people with learning disabilities, families, collective/group advocacy organisations and self advocacy groups in their area to develop policies for people assessing and minimising risks for themselves.
10. The Scottish Consortium for Learning Disability (SCLD) should identify and share good practice in risk management.
11. Local advocacy plans for each area should state how people can get advocacy support on issues such as housing, transport and the other issues that people in that area say are important.
12. Advocacy organisations need to be more proactive in seeking wider funding sources to enable them to provide advocacy to a wider range of people, and should not be solely reliant on one source of funding.
13. The Scottish Executive should give advice to funders that their policies and practices should expect and enable the projects to focus on the needs of the individual. For example, funders should get advocacy projects to build in some flexibility for situations when someone who is already in touch with an advocacy project moves to another area.
14. SIAA should work with advocacy projects to develop advice on ways to build in flexibility so advocacy projects can continue to meet the choices of the people they support.

15. SIAA alongside other appropriate individuals and organisations, should develop national protocols for advocates working with people who do not have capacity.
16. Staff in local authorities and NHS Boards and other people who are implementing the National Standards on Community Engagement should look at how people with learning disabilities and autism spectrum disorders are included as part of community engagement on all issues. As part of this, they should consider how independent advocacy projects can contribute to enabling people to have their voices heard.
17. SIAA and organisations with responsibility for training should ensure training for staff who provide services identifies the importance of independent advocacy and explains their role in working with advocates.
18. Statutory organisations that fund advocacy projects should make sure projects are able to reflect the diversity of the people who want advocacy support. Advocacy projects should have premises that are easily accessible, comfortable and welcoming. There should be partnerships between advocacy projects supporting people who have learning disabilities and projects led by people who share other circumstances. People should be able to have a choice in which advocacy projects they use and in their advocate.
19. Local advocacy plans should specify how children and young people, and older people who have learning disabilities and autism spectrum disorder will get access to advocacy on the points that are important to them, and in a form they find useful.
20. Monitoring local plans should measure the level of service against standards that address the needs of people with learning disabilities and autism spectrum disorders of all ages.
21. Advocacy services need to be flexible to address the different levels of need people have throughout their lives. This will include periods of transition, for example where people are moving into the community as hospitals close, or where children move between special and mainstream or school and college education.

22. Advocacy supports individuals to be included in society and is not just for health and social services. Consideration should therefore be given to the contribution of wider health and local authority departments to funding advocacy services, in order to deliver a whole range of services properly and effectively.
23. Advocacy will also be helpful in achieving full public involvement, moving forward many initiatives such as Modernising Government and creating inclusive communities.
24. Statutory commissioners of services and advocacy organisations need to develop clearer systems for recording who is using advocacy.
25. The SIAA should develop national guidance for monitoring advocacy, to ensure that there is a consistent approach across Scotland.
26. The Scottish Executive should continue to make clear to commissioners that whilst they obviously have a duty to make sure their funds are being used properly, they must allow projects to be appropriately independent and must not try to unduly influence the delivery of advocacy.
27. The SIAA should work with people with learning disabilities and families, advocacy projects and funders, to find ways to describe what advocacy projects do which highlight their benefit for a person with learning disabilities. SIAA should spread the experience of projects and funders that are good at assessing and describing what advocacy projects do.
28. The advice from SIAA and the Scottish Executive should establish that advocates are able to challenge services, the commissioners and their own advocacy project if this is in the interests of the advocacy partner.



Annexes

Annex 1: Policy and legislative context

Introduction

Independent advocacy plays a fundamental role in supporting people to become more involved in the issues that affect them and their communities. In public life the need to be responsive to individual need, to listen to people and to act accordingly is being given a welcome prominence. Independent advocacy is one way of ensuring that everyone has a chance to be listened to and be heard.

Independent advocacy is recognised across a wide spectrum of areas from education, to housing, criminal justice to social work. Independent advocacy supports the diversity agenda and the broader social justice agenda by helping to ensure that everyone in our communities has a voice.

In August 2002, the then Health and Community Care Minister, Malcolm Chisholm, announced £1.3m funding to set up the Advocacy Safeguards Agency and Scottish Independent Advocacy Alliance to develop independent advocacy provision for people in Scotland. Mr Chisholm said:

‘The Scottish Executive is committed to giving the most excluded and isolated individuals in society a stronger voice. Better independent advocacy services will enable people to make informed choices about their own health care and access the information needed to make their views and wishes known.’³

The Labour/Liberal Democrat coalition identified the development of independent advocacy as a key commitment in the Partnership Agreement.

‘We will strengthen patient advocacy services through the Advocacy Safeguards Agency and the Scottish Independent Advocacy Alliance.’⁴

A number of pieces of legislation and several national policy documents are central to the commissioning and provision of Independent Advocacy and have informed the development of Independent Advocacy across Scotland.

3 Malcom Chisholm (2002), *Advocacy Services for Vulnerable Patients*, Scottish Executive News Release SE5312/2002 dated 8 December 2002.

4 Scottish Executive (2003), *A Partnership for a Better Scotland: Partnership Agreement*.

The policy framework

The same as you? (SAY)

The same as you? (SAY) review of services for people with learning disabilities was published by the Scottish Executive in May 2000. It set out 29 recommendations to improve the lives of people with learning disabilities. The Executive consulted with people with learning disabilities, families, carers and people who plan and provide services and supports to find out what would help ensure that people with learning disabilities have the same opportunities as everyone else.

Independent advocacy was identified as an important way of supporting people with learning disabilities. The review found that very few people with learning disabilities have access to an advocate and people who did valued their support.

Recommendation 11 of the SAY review states that:

‘The Scottish Executive should continue to encourage the development of local independent advocacy services.’

The review identified a longer-term aim to:

‘... build towards a position where everyone who has complex needs or is particularly vulnerable has ready access to an advocate.’

Access to independent advocacy was also highlighted in subsequent guidance concerning the implementation of Planning in Partnership Agreements (PIPs).

People with learning disabilities have a right to independent advocacy under the Mental Health (Care and Treatment) (Scotland) Act 2003.

Public Health Institute of Scotland *Autism Spectrum Disorder: Needs Assessment Report*

The PHIS report states that ideal services for people with autism spectrum disorders should include access to advocacy. It also states that:

'Assistance should be given with developing self-advocacy skills and independent, trained advocates should be available to represent the individual if necessary.'

Our National Health: A Plan for Action, A Plan for Change

Our National Health: A Plan for Action, A Plan for Change (Scottish Executive 2000) sets out plans to improve the NHS in Scotland. A survey of over 3,000 members of the public informed the Plan. The need to pay particular attention to the needs of vulnerable people was highlighted.

'While most people who need to use the NHS can speak for themselves, many people from these groups cannot. For some people, we know that independent advocacy services can provide the one-to-one support many vulnerable, excluded people need. We will therefore work with the existing network of independent advocacy organisations across Scotland to ensure that they can deliver high quality, independent advocacy support to nationally agreed standards.'⁵

The Plan cites that by December 2001 we will require all NHS Boards to work in partnership with local authorities to:

'... ensure that integrated independent advocacy services are available to those who most need them.'⁶

Patient Focus Public Involvement (PFPI)

Following the publication of *Our National Health, the Patient Focus Public Involvement (PFPI)* strategy (Scottish Executive 2001) for involving patients and the public more effectively in the NHS was published. The provision of independent advocacy is a key requirement in the delivery of the PFPI agenda. Independent advocacy was recognised as an important way of supporting people's involvement in their care and treatment.

⁵ Scottish Executive (2000) *Our National Health: A Plan for Action, A Plan for Change*.

⁶ Scottish Executive (2000) *Our National Health: A Plan for Action, A Plan for Change*.

To monitor implementation of this requirement, NHS Boards (including special Boards) were required by the Scottish Executive to produce three-year advocacy plans for the period 2001-2004. The first edition of ***Independent Advocacy: A Guide for Commissioners*** was published by the Scottish Executive in January 2001 to support commissioners in developing independent advocacy provision across Scotland. Three-year plans for the period 2004-2007 have been submitted to the Scottish Executive. NHS Boards will have to evidence delivery and levels of investment as part of contract monitoring arrangements.

The ***Performance Assessment Framework*** for annual assessment of Boards' progress towards implementing *Our National Health* was introduced in 2001. The section measuring PFPI includes indicators for independent advocacy provision. In April 2005 responsibility for assessing NHS Boards' progress will move to the Scottish Health Council.

The 2003 Scottish health white paper ***Partnership for Care*** builds on the foundations laid in the earlier document *Our National Health: A Plan for Action, A Plan for Change* and reinforces the commitment of the Ministers and the Scottish Executive Health Department to involving people and communities in the centrality of health service planning and delivery.

Fair for All

Ensuring that services are effective for people whatever their personal circumstances or background is important. Independent advocacy is recognised as one way of supporting this to happen. It is essential that independent advocacy services are themselves inclusive and accessible to people who their services are aimed at.

NHSScotland published the ***Fair for All*** strategy to highlights its commitment to ensuring that people are treated (whether as patients, staff, visitors or volunteers) without discrimination related to their age, gender, racial origin, sexual orientation or religious belief. It is important that advocacy services are equally available to all who need them and provided in a non-discriminatory way in line with the Executive's social inclusion agenda.

Within the NHS the *Fair for All* initiative launched in 2000 to support NHS Scotland to become more patient-focused recognised the need for independent advocacy.

Partnership for Care extended the principles of the *Fair for All* approach across the NHS to ensure that:

‘...our health services recognise and respond sensitively to the individual needs, background and circumstances of people’s lives.’⁷

The progress of NHS Boards was reported in September 2003 in *Fair Enough? Fair for All Progress Report*.

Fair for All found that independent advocacy is important in delivering a patient-focused health service. The 2003 progress report found that only half of race equality schemes had a satisfactory level of advocacy in place. The progress report emphasized the need to ensure that the advocacy already available in all Local Health Care Cooperatives (LHCCs) should be inclusive of black/minority ethnic needs. The need for evaluating service uptake, provision and satisfaction was highlighted.

National Standards for Community Engagement

The effective engagement of local people is critical to the regeneration of our most disadvantaged communities by local partnerships. **The National Standards for Community Engagement** have been developed with the involvement of over 500 people from communities and agencies throughout Scotland. They are a practical tool to help improve the experience of all participants involved in community engagement to achieve the highest quality of process and results. Advocacy has an important role to play in community engagement and ensuring people with learning disabilities and autism spectrum disorders have the opportunity to have their voices heard in their own communities.

All organisations implementing the standards must commit to identifying and overcoming barriers to participation in community engagement and actively promote the involvement of people who experience these barriers. The use of advocacy can overcome the barriers faced by some people with learning disabilities and autism spectrum disorders.

⁷ Scottish Executive (2003), *Partnership for Care: Scotland’s Health White Paper*.

The Legislative Framework

Education (Additional Support for Learning) (Scotland) Act 2004

Section 14 of the Additional Support for Learning Act states that education authorities carrying out duties under the Act must conduct discussions with a young person's advocate where a child's parent or a young person wishes it and 'must comply with the 'relevant person's wishes, unless the wishes are unreasonable' (14 (1)(b)). However, it also states that: 'nothing in subsection (1) is to be read as requiring an education authority to provide or pay for a supporter or advocate' (14(3)).

While there is no duty to provide advocacy under the ASL Act, there is a duty to provide advocacy to children and young people with a mental disorder under the MHA. As some children and young people who have additional support needs may also have a mental disorder it would be advisable for statutory commissioning bodies to have regard to the needs of both groups.

The Mental Health (Care and Treatment) (Scotland) Act 2003

The Mental Health (Care and Treatment) (Scotland) Act 2003 gives people with a 'mental disorder' a right to independent advocacy.

The Act places a duty on NHS Boards and local authorities to secure the availability of independent advocacy services and to take appropriate steps to ensure that those persons have the opportunity of making use of those services.

Clearly, commissioning bodies have a legal obligation to ensure that independent advocacy is available and that people who wish to access advocacy support can do so. The right applies to everyone who has a mental disorder, to both group and individual, independent advocacy services. The term '*mental disorder*' is defined in section 328 of the Act and includes any person with: a mental illness; a personality disorder and a learning disability. People with dementia and acquired brain injury are also covered by the Act.

In summary, the right to access independent advocacy applies to anyone person who has a mental disorder regardless of: age, disability, ethnic origin, culture, faith, religion, sexuality, social background or personal circumstances; whether or not they are subject to compulsion and whether or not they are ordinarily resident in Scotland.

Community Care (Direct Payments) Act 1996

The Policy and Practice Guidance issued to local authorities by the Scottish Executive in June 2003 on the implementation of Direct Payments states that:

'129. It is essential that local authorities ensure that people are able to access an independent advocacy service in their area. Local authorities must ensure that independent advocacy plays a role in the successful operation of direct payments. Where local support organisations also provide an independent advocacy service it is important that the operations are kept entirely separate.

130. In general, independent advocacy can help to:

- promote respect for the rights, freedoms and dignity of people, both individually and collectively;
- ensure people receive the care or services to which they are entitled, and which they wish to receive;
- enhance people's autonomy;
- assist people to live as independently as possible and in the least restrictive environment; and
- help protect disadvantaged people from abuse and exploitation.

131. The Minister for Health and Community Care has been explicit in his expectation that all NHS Boards, in partnership with their local authority planning partners, should ensure that independent advocacy is available to all those that need it.

Statutory commissioners should ensure advocacy development plans include provision for people who are eligible for direct payments. This includes people who have not made a decision to take up direct payments but may wish to have support in considering this option.'

Standards

Principles and Standards in Independent Advocacy Organisations and Groups

The *Principles and Standards in Independent Advocacy Organisations and Groups* was published by Advocacy 2000 in January 2002. The purpose of this document is to describe what effective independent advocacy is about, and sets out the key principles and standards of Independent Advocacy as it is practised in Scotland. It describes the key principles, standards and outcomes for all independent advocacy organisations and specific ones for the three main models of independent advocacy (individual professional (paid and volunteer); citizen and collective and self-advocacy groups).

The Scottish Executive Health Department now has lead responsibility for this document and is currently in the process of updating this document. A new document will be produced in spring 2006.

The Regulation of Care (Scotland) Act 2001

The Regulation of Care (Scotland) Act 2001 set up the **Scottish Commission for the Regulation of Care** (The Care Commission), which inspects and regulates care services by taking account of the **National Care Standards**. These include Standards that have been developed for advocacy.

National Care Standards were developed for every care service regulated by the Care Commission and are published and reviewed by the Scottish Executive. They have been developed from the point of view of people who use care services and they describe what each person can expect from their service providers. Copies of the standards can be downloaded from the Scottish Executive website.

Care services regulated by the care commission include: adoption agencies, care homes, adult placement services, care at home, childcare agencies, pre-school education, boarding school care, foster care and family placement services, housing support services, care and welfare in accommodation for offenders, hospice care, independent hospitals and clinics, nurse agencies and short breaks and respite care.

The standards for advocacy are:

- You are encouraged and supported to use an independent and confidential advocacy service that can act for you. Staff will have information about any service that would help you in this way.

- If you have an independent representative (for example an independent advocate), staff will listen to what he or she has to say on your behalf, as if you were expressing the views yourself.
- If you belong to an advocacy group, staff will take seriously suggestions or proposals that come from the group.

Commissioners should take steps to support commissioned service providers to meet these standards.

NHS Quality Improvement Scotland (NHS QIS)

The purpose of NHS Quality Improvement Scotland (NHS QIS) is to improve the quality of healthcare in Scotland by setting standards and monitoring performance, and by providing NHSScotland with advice, guidance and support on effective clinical practice and service improvements.

A part of this remit is to develop and run a national system of quality assurance of clinical services. Working in partnership with healthcare professionals and members of the public, NHS QIS sets standards for clinical services, assesses performance throughout NHSScotland against these standards, and publishes the findings. The standards are based on the patient's journey as he or she moves through different parts of the health service.

All NHS QIS standards include reference to the provision of independent advocacy in the delivery of health services.

NHS QIS Draft Standards – January 2004 Healthcare Governance: Working Towards Safe and Effective, Patient-Focused Care cites:

'2. STANDARD: Delivering Services – "how we work together"'

2.2 Patient focus public involvement (PFPI)

NHS Boards must respect the views and needs of individuals, the wider public and local communities, and reflect this within their strategies. They will provide:

- *Advocacy services that are available to all users and potential users of their services ... and have in place advocacy policy(s).'*

NHS QIS will monitor this commitment as with all Healthcare Governance Standards.

Annex 2: Person-centred services – good practice

Person-friendly services

The same as you? described how people should be involved in decisions about their lives:

At the centre of this is a major shift to person-centred and needs-led approaches, which the individual at the heart of any decisions made. For that to work, people with learning disabilities and autism spectrum disorders need better information to make more informed choices, to be supported by an advocate if they want, and to have more control over their lives and services.

(The same as you? 2000 p. 107)

When services reflect the principles in *The same as you?*, they should be centred on the person. The starting point is that services should respect people, listen to them and act on what they hear.

By services, we mean all services which people with learning disabilities and people with autism spectrum disorders use. This includes health and social care services that focus on the needs of people with learning disabilities and autism spectrum disorders, the general health and local authority services that everyone uses, and services like shops, housing, transport and leisure facilities which are provided by a wide range of people.

Why this matters

We think these are the features of a good service.

- It values each person.
- The staff think about what will work for each person.
- It is easy for someone to ask for what they want.
- Staff encourage people to ask, and think of ways which will make it easy for someone to communicate in the way they find comfortable.
- Staff realise that it isn't easy for people to raise points if they are not used to being listened to, or if the matter worries them.
- Staff listen to what people say, and act on it for that person.
- When something isn't right, staff work to put it right as quickly as possible. They tell the person what is happening.
- The service works in partnership with people who use it and with families and other people, including advocacy projects, to try to make things work as well as possible.

- Staff think about what they are hearing from the people who use their service. They use the feedback from one person to also improve the service for other people.
- Staff make a real effort to find out what things are important in a person's life and act positively upon them.

The service works around the needs of the person. It does not expect people to work around what suits the service.

There are now many other standards which expect various services to respond to the needs of individual people.

Services should work well for everyone. Good services aim to work well for the people who have the most need, for people who find it hard to explain what they want, and for people who have few other people in their lives to help them get what they need.

They also recognise that some people need some extra help to explain what they want – which is why the arrangements for people speaking up for themselves and advocacy are essential.

Other ways for people to have a say

During the past few years the Scottish Executive has been encouraging public services to do more to involve the people who use their services and people in the local community generally. These arrangements should give people with learning disabilities more say in the services they get.

There have been particular efforts in health services – called *Patient Focus and Public Involvement*. Each NHS Board has a strategy for involving people, and there are many local projects such as patients' reference groups. The Scottish Executive is also requiring health services to do more to make sure that services work for individual people – especially people with disabilities, people from minority ethnic groups and other people who often feel left out.

***The same as you?* – new ways of working**

Implementation of *The same as you?* across Scotland is demonstrating new ways of working and new roles for individuals with learning disabilities and autism spectrum disorders, family carers, and for professionals. The following sections describe work in Fife and the experience of local area co-ordinators.

Say Project

Active Partnership

Our key objective is to engage the people of Fife in identifying what needed to change first and to enlist their assistance to make these changes happen. Four major stakeholders conferences were held and 11 key themes for change were identified. 11 working groups were set up to take necessary actions to realise the changes.

Each working group has diverse membership with people who use services, parents, carers as well as staff from the voluntary and statutory sector playing their part.

Some of the working groups are chaired by parents, some by people who use services and others by officers. Everyone has an equal place at the table and an equal voice. Administrative support, a budget and facilitation where necessary was built in at the beginning so that the groups had real power, real influence and a real voice. Many innovative projects have been devised and created by the working groups. These include:

- Liaison nurse post established for people with a learning disability
- A cookbook to encourage health eating for people who have difficulty with reading
- Improved availability of learning disability information in local libraries
- Improved leisure facilities for people with profound learning disabilities through partnership working with Fife Tourist Board and Fife Community Services
- An advocacy service throughout Fife
- A joint postural management service for people with complex care needs
- A Moving On booklet designed to help young people and families through the transition to young adulthood
- Over 1000 people undertook person-centred planning training with people who use services, family carers and staff training together

Empowerment

To properly involve and empower people, we realised that we needed to invest in those people. We wanted to reach a point where adults with a learning disability felt confident and comfortable in taking part in committee meetings, Board meetings, speaking at major conferences and ensuring that their voice was heard in every process.

'It's Your SAY' was set up to help us achieve this. Adults with a learning disability who wish to take on these kind of activities have been identified and local area committees set up. Training from St Andrews University has assisted in developing people's capacity and confidence. Already individuals from the groups are helping us design recruitment processes and are involved in formal recruitment interviews for staff at all levels in the service. They are also members of the SAY Board, a multi-agency steering group for the SAY Project and most recently they have connected with Dundee University School of Social Work to assist first year social work students develop awareness about the wishes and aspirations of people with learning disabilities.

Over time, these local committees will actively contribute their views and ideas and shape the policies and procedures within the statutory agencies in Fife. In that way those agencies will know that they are doing the right things, in the right way, at the right time.

Local area co-ordination

Another recommendation of *The same as you?* was the establishment of Local Area Co-ordination as a new way of working with people with learning disabilities. In some local areas, Local Area Co-ordinators (LACs) were appointed simultaneously with Co-ordinators of independent advocacy services. In these areas Local Area Co-ordination and Advocacy have complemented each other with individual Co-ordinators having good communication and awareness of their different roles.

Some LACs have completed advocacy training to help ensure their understanding of relevant issues.

There are circumstances in which LACs may, for some individuals, perform 'advocacy' tasks in their effort to be person-centred and respond to the wishes of the individuals that they support. LACs will also participate in group advocacy, campaigning for the rights of all individuals with learning disabilities to be included in the wider community.

However, as most but not all LACs are employed by the local authority, they are well aware of the potential conflict this could create where the individual may have a complaint about the local authority services. LACs recognise the limits to their independence and will readily refer people to independent advocacy services in such cases.

LACs are also trying to balance the needs and wishes of people with learning disabilities and their family carers. Where there is a potential conflict of interest between the views of the individual with the disability and their parent or carers, there may be a need for more than one advocate to be involved as both may require support to express their views and negotiate a solution. LACs may act as informal advocates for one party in such situations, especially when there are not enough trained independent advocates available.

This has been highlighted by a situation when a family who had been supported by the LAC found themselves in a very sensitive and stressful situation. There were major issues with most of the people concerned and the family found themselves separated for some weeks each not knowing or fully understanding what was going on. The LAC had to take on board the issues this brought and find ways to negotiate and advocate for both the people concerned. This was a situation where more than one advocate was required and where eventually the independent advocate came on board.

On reflection of the situation the role of advocacy and the important part it plays is still in the early stages of understanding by both people wanting to use the service and also with professionals who could benefit by the support advocacy can have on such sensitive issues as family relationships.

Other moves to improve services

Other things have happened to improve the services that people with learning disabilities receive. Several bodies have been set up or given more powers in the last few years:

- The Care Commission, which sets the standards for social care services – such as home support and residential care. It also inspects services, to see that the standards are met.
- NHS Quality Improvement Scotland, which sets standards for all health services, and will also be carrying out reviews.
- The Scottish Social Services Commission, which says what training social workers and support staff need to have.
- NHS Education Scotland, which says what training health care staff need.
- Disability Rights Commission, which will see that the Disability Discrimination Act is implemented throughout the UK. This affects all of the services people with learning disabilities use – ordinary and mainstream services as well as health and social care services.

Annex 3: Resources – organisations and other useful info

Scottish Independent Advocacy Alliance

The Scottish Independent Advocacy Alliance (SIAA) is a registered charity funded by the Scottish Executive Health Department.

The SIAA is a membership organisation for advocacy groups and other organisations with a commitment to independent advocacy. The SIAA supports the advocacy movement by promoting the importance of diversity and high quality advocacy alongside strong principles and standards across Scotland.

1. **Providing a strong national voice for independent advocacy organisations** The SIAA promotes the value and worth of advocacy to planners and decision makers. It consults with, and on behalf of, the advocacy movement regarding changes and developments in policy, legislation and practice.
2. **Supporting the growth of existing independent advocacy organisations** The SIAA supports and assists advocacy organisations with regards to funding, growth/development, good practice and consultancy. It supports advocacy organisations in the process of becoming independent. It aims to strengthen the advocacy movement through the sharing of ideas, good practice and support.
3. **Promoting the development of new independent organisations** The SIAA researches and identifies gaps in independent advocacy. The SIAA supports the development of new organisations and will help them to achieve independence.
4. **Awareness Raising and Training** The SIAA raises awareness about advocacy by providing training around the role of the advocate, the impact/value of advocacy and the appropriate expectations of an advocate to commissioners, service provider staff, users, carers and other professionals who come into contact with advocates. The SIAA also provides capacity building training for advocates

Scottish Independent Advocacy Alliance

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e-mail: enquiry@siaa.org.uk

Annex 4: Spend on advocacy and learning disabilities

The following figures were obtained from three-year plans for the period 2004-2007 which were submitted to the Advocacy Safeguards Agency. The total amount of statutory funding specifically allocated to advocacy for people with a learning disability in 2005/06 is £2,049,602 (Chart 1), this represents 26% of the £8,060,541 total statutory funding for advocacy allocated in 2005/06 (Chart 2).

Chart 1. Local authority and NHS spend on advocacy for people with learning disabilities

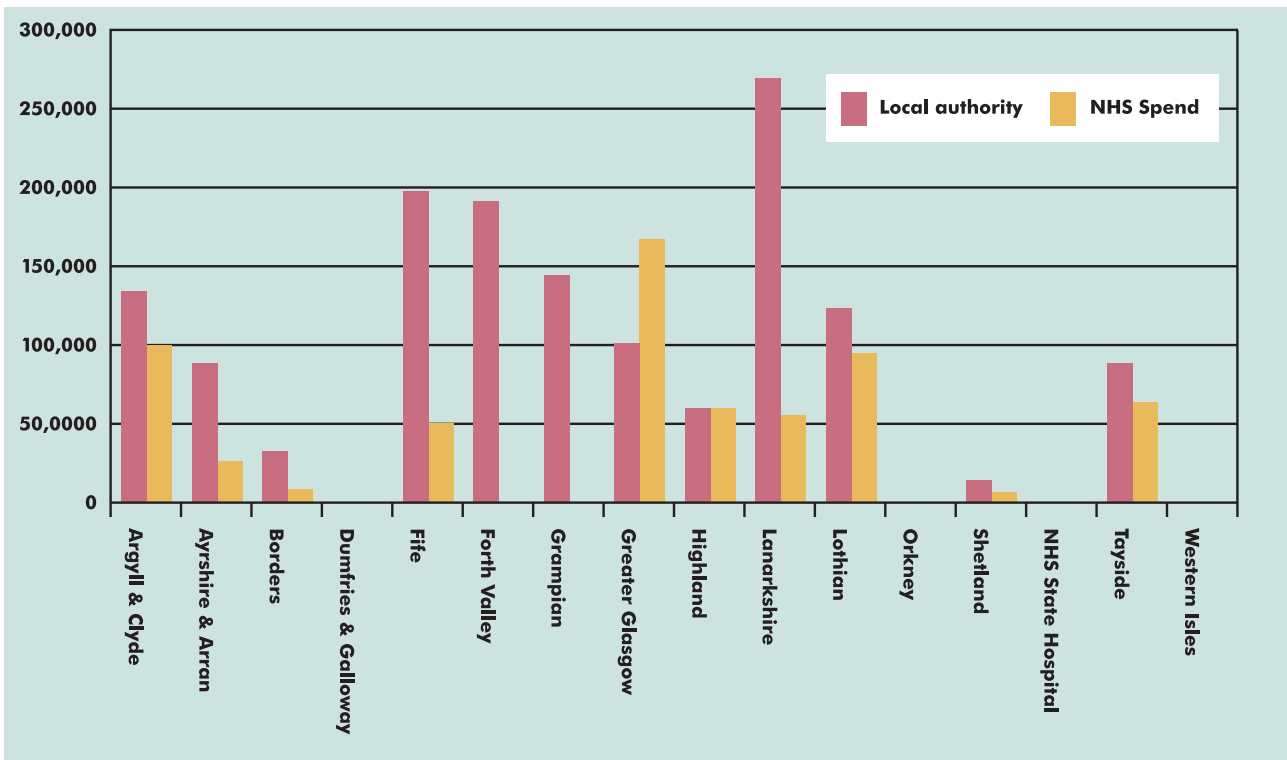
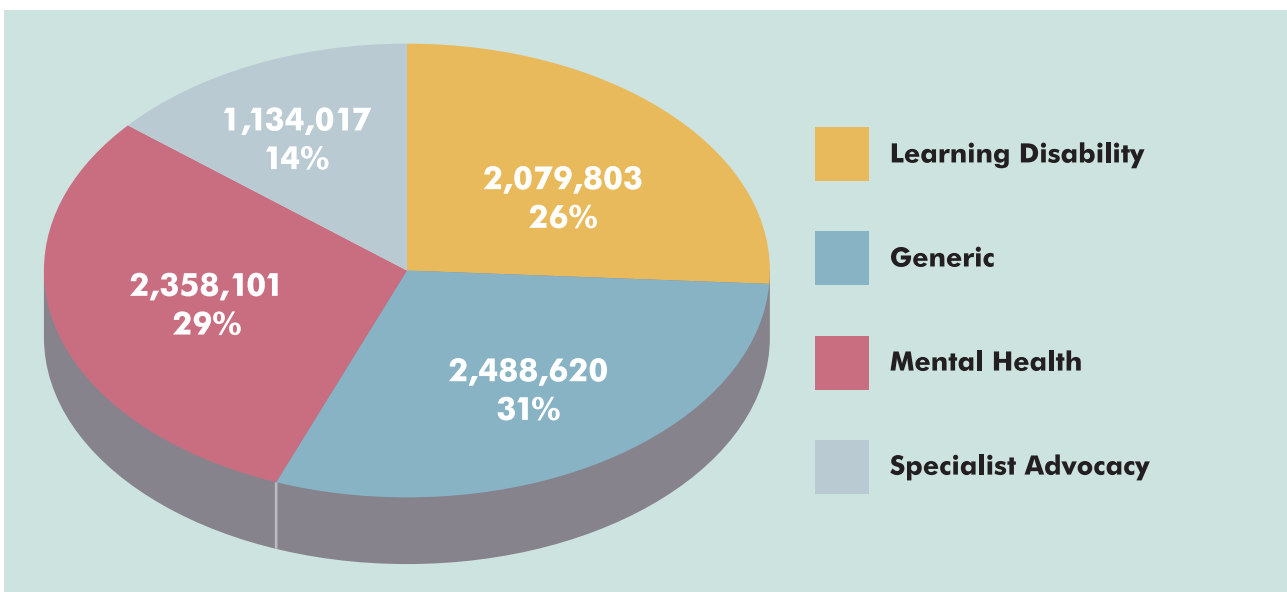


Chart 2. Types of advocacy 2005-06



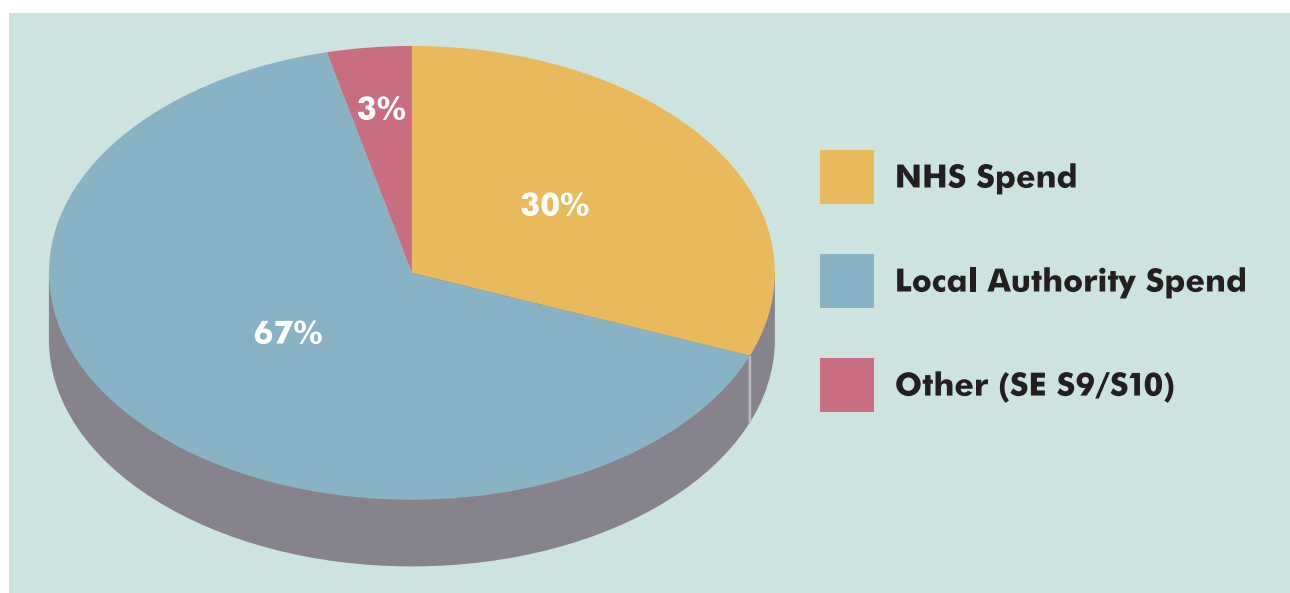
Advocacy is also available to people with a learning disability via generic advocacy organisations and advocacy organisations for people with a mental disorder. If you include the advocacy funding for these types of advocacy, the spend is greater.

The total amount of statutory funding allocated to advocacy organisations that are accessible to people with a learning disability in 2005-06 is £6,926,524, this represents 86% of the total statutory funding for advocacy in 2005-06.

There are also a number of advocacy organisations which provide advocacy to specific groups, such as children and young people, older people, people from black and ethnic minority communities, people affected by HIV, and carers. These groups will obviously include people with a learning disability, and it is highly likely that people with a learning disability may access these advocacy organisations that are 'group' specific. The total amount of statutory funding allocated to these advocacy organisations in 2005-06 is £1,134,017, this represents 14% of the total statutory funding for advocacy in 2005-06.

Chart 3 shows the breakdown of expenditure on learning disability advocacy into NHS spend and local authority spend.

Chart 3. Spend on learning disability advocacy



Annex 5: Summary of questionnaire responses

A questionnaire asking about people's experiences of advocacy was completed by 58 people with learning disabilities, 4 people from local autism groups and 20 parents and carers.

Responses from people with learning disabilities in local areas

50 of those people with learning disabilities who responded to our survey said there had been times when they wanted to have someone help them ask for what they wanted.

The kinds of people they used to help them get what they wanted included support workers, parents and other family members, advocates and self-advocacy groups.

Issues where people with learning disabilities and families said they wanted some extra help to say what they wanted included:

- employment
- housing
- transport
- education
- moving from school and children's services to adult life and services
- health services
- social work services
- assistance with social integration and using ordinary community services
- access to services to support people with learning disabilities in their role as parents
- financial services
- police and community safety services.

Over half of those looking for independent advocacy were able to get it when they needed it. However, 17 people said they were unable to access advocacy services for a number of reasons including:

- there are not many workers
- long waiting lists
- sometimes people do not know advocacy is available
- transport can be a barrier
- there are less advocates in rural areas

Only half the people responding to the survey thought that staff in services understand about advocacy. Some people found that when they made a suggestion or asked for something the organisation or individual staff saw it as a complaint or criticism.

'It is not easy saying what you want to. Sometimes I am a bit worried about upsetting workers so it is really good to have someone else to help you.'

Many people found that staff who work in a wide range of services – including specialist learning disability services – had low expectations of what people can do and didn't expect that people with learning disabilities would have views.

Some staff seem to make their decision about what people needed on the basis of their experience or what other people said, and did not listen to people's views. Some people felt they had few opportunities to speak up for themselves, and therefore could not get information about plans for services.

'If I didn't come to the People First group I wouldn't know what was happening about the hospital closing. No one tells us [residents] anything.'

Responses from parents and carers

More than half of the parents and carers surveyed said there have been times when they wanted to have someone help them ask for what they wanted. The same number said there had been times when their relative needed access to advocacy.

As with the surveys answered by people with learning disabilities, only half of the parents and carers or their family member have been able to get independent advocacy. This was for similar reasons, ie. lack of advocacy provision and lack of knowledge about what is available.

Of those people who used an advocacy service, almost all thought the support they received had been good:

- 'I no longer felt alone.'
- 'She got to know him, took time with him, found ways to communicate, when everyone else tried to decide his future without knowing him or what he wanted.'

- ‘They have provided tremendous support by giving advice, attending interviews, travel to and from work and attending his work placements.’

Some parents expressed concern that advocacy service is often not available for people under 18.

Responses from people in local autism groups

The responses from people in local autism groups gave a different picture to those from people with learning disabilities and their families.

All of the people from local autism groups who were surveyed said there were times when they wanted help asking for what they wanted, yet all had been unable to get independent advocacy.

None of those surveyed felt that advocacy projects understand the needs of people with autism. One person commented that advocacy would make a big difference to their life – they just need a suitable service.

Some people found that because their disability is not visible other people were not aware of it – this is a problem for many people who have an autism spectrum disorder.

What difference has advocacy made to people’s lives?

- ‘I can speak about everything in safety. I have more confidence and a sense I am not alone.’
- ‘It helped me get what I wanted.’
- ‘It gives you a greater voice to make a real difference and make better choices.’
- ‘I didn’t feel so angry and it was easier to speak to the workers.’
- ‘Our son and daughter are getting more help and are treated better.’
- ‘We have more time to have quality time as a family without having to worry about dealing with numerous forms, red tape and official departments.’

Annex 6: Advocacy group members

Andrew Doyle, ENABLE

Andy Miller, Scottish Consortium for Learning Disability

Anne Connor, Outside the Box Development Support (Chair)

Angela Gilchrist, Local Area Co-ordinator, Argyll and Bute

Cindy Wallis, NHS Argyll and Clyde

David Cameron, Advocacy Standards Agency

Donald Macaskill, Equal & Diverse

James McNab, People First Scotland

Jimmy McIntosh, Edinburgh Development Group

Julienne Dickey, Partners in Advocacy

Morag Chrichton, Dundee City Council

Rachel Annand, Dunfermline Advocacy Initiative

Roseanne Fearnon, Fife Council

Shaben Begum, Scottish Independent Advocacy Alliance

Shabnum Mustapha, National Autistic Society

Tommy Redpath, Fair Deal for 1 in 100

Annex 7 Strategies for effective advocacy for people with ASD

How ASD affects a person's communication

- Non-verbal
- Limited communication
- Absence of desire to communicate
- Echolalia and repetitive speech
- Confined to expression of needs only
- Factual comments irrelevant to conversation
- Talking incessantly regardless of response
- Better expressive language than receptive language – not understanding language

Strategies

- Use clear, unambiguous language
- Use short sentences separating out different ideas e.g. Ask your sister if she wants a cup of tea and then come and tell me what she said
- Limit non-verbal communication
- Do not use metaphors or colloquial speech
- Sarcasm and irony are confusing
- Remove uncertainty, use visual tools like a visual diary
- Tell the person who you are, what you can and can't do, how long you will be with them, how they can contact you and when

How ASD affects a person's social interaction

- Inability to interact with peers
- Lack of desire to interact
- Doesn't understand social cues
- Socially inappropriate behaviour
- Difficulty in understanding and expressing feelings
- Emotionally inappropriate behaviour
- Poor ability to make and maintain friendships

Strategies

- Take time to find out what is important to person and how they want to interact
- Use person's own interests
- Focus on one thing at a time
- Don't raise expectations that cannot be fulfilled as this will create anxiety
- Explain the 'rules'
- Explain how they apply in each situation

How autism affects a person's imagination

- Difficulty in understanding that other people may see things from a different viewpoint
- Repetitive re-enacting of role often copied without understanding purpose behind actions
- Difficulty in generalising concepts – literalism in understanding spoken language
- Difficulty in understanding abstract concepts – cause and consequence

Strategies

- Do not assume the person knows what you intend to do next
- Don't take for granted they know the next step in a sequence of events
- Limiting choice
- Role play situations before they occur
- Use photos or video to help understand sequence of events
- Support the person each time they encounter a change

Other factors

- Ritualistic behaviour
- Overlapping conditions e.g. ADHD, Tourettes, Mental Illness
- Sensory issues – hypersensitivity to noise, touch, smell – environment

Positives

- Good visual skills
- Excellent factual memory
- Precision and accuracy
- Attention to detail
- Adherence to 'rules'
- Strong sense of 'right' and 'wrong'

How might all of this make advocacy difficult?

- Wide diversity of ability – a spectrum disorder
- Difficulty in understanding different view points and abstract concepts – and therefore options, cause and consequence
- Difficulty in organising and planning ahead
- Resistance to change – irrational fears, high anxiety, ritualistic behaviour
- Difficulty in forming relationships
- Difficulty in communication and understanding e.g. linking separate sentences to make meaningful statements

Issues to consider

- Type of advocacy needed
- Advocacy approach: structured, clear, consistent
- Communication and non-instructed advocacy
- Mental capacity and decision making legislation
- Choice and introducing changes

What people with ASD tell us they want in an advocate

- Trust and confidence. The right to choose an advocate where possible
- Accountability
- A good advocate should make you feel better even if you have not been successful, because they put your case forward well
- Patience and assertiveness
- Some people with ASD can be advocates, they just use different techniques – they need the person to be clear, as they cannot read body language etc.
- Determine when a volunteer or paid advocate is needed
- Ask the person what kind of advocate they want

In other words an advocate needs: knowledge, tenacity, skills, and resilience and a lot of common sense.

The National Autism Society runs a national Helpline, which receives 35,000 calls a year. Many of our callers would benefit from advocacy, and we do often refer on to advocacy organisations. The main issues people need help with are:

- Education
- Benefits
- Community care and access to services and support
- Health services

Annex 8: Glossary of terms – from *The same as you?*

Advocate/ Advocacy	Someone who helps people with learning disabilities to say what it is they need and to make their own decisions. See citizen advocate and self-advocacy.
Asperger's syndrome	This is a type of autism (see below) that some people of average intelligence and language ability have. They find it particularly difficult to understand what other people think and this makes it hard for them to communicate and act appropriately.
Autism spectrum disorder	A lifelong, complex condition resulting in mild to severe social, language and communication, and thought and behavioural impairments.
Benchmarking	Working out how good a service is by comparing it to another service that has set a high standard.
Care Programme Approach	A way of making sure that all those with serious mental health problems and complex needs have an assessment and care plan that all the different professionals agree on (for example, social workers and doctors). This is checked regularly to see how well the person is doing.
Challenging behaviour	A term used to describe when someone is acting in a way that might do themselves or others harm. People who care for these people are 'challenged' to stop the harm. That is why we call it ' challenging behaviour '.
Citizen advocate	An 'unpaid' volunteer who is independent of the services, a person with learning disabilities receives. This advocate represents the needs of the person and supports them to make sure they get their rights.
Commissioning	Deciding what services are needed and then getting someone to provide these by signing a contract.
Complex needs	This describes the needs a person has over and above their learning disability. For example, extra physical or mental health problems, challenging behaviour or offending behaviour.
Continuing care	Nursing or medical help or both of a level that cannot be provided in a care or nursing home.

Detained patient	Someone who is made to stay in hospital under a section of the Mental Health (Scotland) Act 1984 or the Criminal Procedure (Scotland) Act 1995.
Direct payments	Local authorities giving people money to buy their own social care services so that they have more say in how their needs are met.
Dual diagnosis	Where someone has both a learning disability and mental health problems.
Early onset dementia	A term used to describe people who get dementia at an earlier age than might be expected. This leads to a variety of problems, including difficulties in remembering, making decisions, and learning new skills. These difficulties get worse as time passes.
Guardian/ guardianship	A guardian for a child is someone appointed by a parent, or, where necessary, the sheriff, to take over parents' responsibilities and rights after a parent dies. The guardian's role applies until the child is 18. A guardian for an adult with a mental disorder is someone appointed by the sheriff who has the power to say where the person lives, gets education and training and also makes sure that doctors can see a person without difficulty.
Learning difficulty	Pre-school and school-age children are usually described as having a learning difficulty rather than a disability when they have special educational needs that need extra or different approaches to the way they are taught.
Multiple disability needs	Where someone needs help with several aspects of life which may include health, education, leisure, financial or housing support and being part of the community.
Natural supports	People who help those with learning disabilities like family and friends and are not paid to do this.
Profound disability needs	A term used to describe someone who has a very severe degree of learning disability which may be associated with complex needs. For example, this could include feeding difficulties, physical disabilities or sensory impairment .

Psychotherapy	A psychological treatment based on talking and usually designed to help the person understand what is happening now and how to change it.
Revenue	Money spent on day-to-day costs like paying for staff and services.
Self-advocacy	Where people with learning disabilities promote their needs and wishes for themselves.
Sensory impairment	A loss of sight or hearing or both.
Social inclusion	Helping people to feel and be part of the society in which they live. They are 'socially included'.



SCOTTISH EXECUTIVE

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